

Training in positivity for stroke? A qualitative study of acceptability of use of Positive Mental Training (PosMT) as a tool to assist stroke survivors with post-stroke psychological problems and in coping with rehabilitation

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Abstract

BACKGROUND: Post-stroke psychological problems predict poor recovery, while positive affect enables patients to focus on rehabilitation and may improve functional outcomes. Positive Mental Training (PosMT), a guided self-help audio shows promise as a tool in promoting positivity, optimism and resilience.

OBJECTIVE: To assess acceptability of training in positivity with PosMT for prevention and management of post-stroke psychological problems and to help with coping with rehabilitation.

METHODS: A modified PosMT tool consisted of 12 audio tracks each lasting 18 minutes, one listened to every day for a week. Survivors and carers were asked to listen for 4 weeks, but could volunteer to listen for more. Interviews took place about experiences of the tool after 4 and 12 weeks. Subjects: 10 stroke survivors and 5 carers from Stroke Support Groups in the UK.

RESULTS: Three stroke survivors did not engage with the tool. The remainder reported positive physical and psychological benefits including improved relaxation, better sleep and reduced anxiety after four weeks. Survivors who completed the programme gained a positive outlook on the future, increased motivation, confidence and ability to cope with rehabilitation. No adverse effects were reported.

CONCLUSIONS: The PosMT shows potential as a tool for coping with rehabilitation and overcoming post-stroke psychological problems including anxiety and depression.

Key Words Stroke, rehabilitation, rehabilitation interventions, positivity, depression, anxiety, qualitative analysis, semi- structured interviews

Introduction

As the population in developed nations age, the burden of stroke, already a significant cause of disability, is expected to rise. (World Health, 2000) The presence of psychological problems including psychological distress, anxiety or depression frequently interferes with stroke rehabilitation and is an independent predictor of recovery, functional outcome and quality of life as well as mortality after stroke. (Ellis, Zhao, & Egede, 2010; Kim, Warren, Madill, & Hadley, 1999) About a third of survivors of stroke suffer from clinical depression, nearly a quarter with anxiety, and many more with psychological distress and problems adjusting to post-stroke life that do not reach clinical criteria for a mental health disorder. (British Psychological, 2010; Campbell Burton et al., 2013; Hackett, Yapa, Parag, & Anderson, 2005) Adequate services for post-stroke psychological care of survivors within rehabilitation care are however often lacking. (National Audit Office, 2005, 2010) Limitations in services include access to expertise and staff, and lack of evidence-based interventions. (NHS East of England, 2010) Management of post-stroke psychological problems including depression and anxiety that hinder rehabilitation present a unique challenge to services since such problems may be attributed not only to the consequences of physical, social and financial disruption but also to biological damage of the brain after stroke. (House, Dennis, Warlow, Hawton, & Molyneux, 1990) Studies nevertheless suggest that for many survivors it is the helplessness, hopelessness and the feeling that there is little they can do for themselves that may be most associated with poor stroke rehabilitation outcomes. (Lewis, Dennis, O'Rourke, & Sharpe, 2001; Morgenstern et al., 2011) Many stroke survivors prefer self-help and psychological approaches to management of their psychological problems after stroke and are reluctant to be medicalised and to take antidepressant medication. (Stroke

Association Report, 2013) Psychological interventions to reduce post-stroke psychological problems including psychological distress, anxiety and depression, and to help with coping have however, not always been successful. (Hackett, Anderson, House, & Xia, 2008; House et al., 1990) Cognitive Behavioural Therapy (CBT) has shown promise with improving depression but requires mental effort on the part of the survivor during and outside the treatment session and there are not always staff qualified to deliver it. (I. I. Kneebone & Dunmore, 2000; I.I. Kneebone & Jeffries, 2013; Kootker et al., 2015) Wellbeing approaches such as mindfulness training and relaxation therapy show promise in the stroke population. (Golding, Kneebone, & Fife-Schaw, 2015; Johansson, Bjuhr, & Ronnback, 2012; Lawrence, Booth, Mercer, & Crawford, 2013) Such approaches, however, often require intense training for greatest effect. There is a potential role for interventions for post-stroke psychological problems to help with coping with the stressors of rehabilitation that are evidence-based, simple and not costly to deliver.

Interventions that promote positive affect have potential for improving the psychological state of people with chronic health conditions and comorbid psychological problems.(Pressman & Cohen, 2005) These have however not been extensively evaluated in stroke survivors. It is hypothesised that such approaches counter the effects of negative mood and increase self-efficacy, coping strategies and sense of control, enabling patients with disability to focus on their rehabilitation needs. (Partridge & Johnston, 1989; Pressman & Cohen, 2005) Indeed positive affect in the context of stroke has been associated independently with improved functional status, lower post-stroke pain, increased social participation and reduced mortality. (Berges, Seale, & Ostir, 2011; Berges, Seale, & Ostir, 2012; Ostir, Berges, Ottenbacher, Clow, & Ottenbacher, 2008)

Positive Mental Training (PosMT) is a guided self-help treatment consisting of a 12 week audio training in positivity, optimism and resilience that has shown promise in improving anxiety and depression in patients in primary care. (Dobbin, Maxwell, & Elton, 2009) It incorporates therapeutic techniques from relaxation, mindfulness and positive psychology to generate positive feelings, allowing listeners to overcome negative thinking patterns and become more positive, confident and resilient. Over 70,000 patients have already received the tool in the NHS in Scotland and other parts of the UK including those with a range of chronic co-morbid physical and mental health conditions.(www.foundationforpositivementalhealth.com) PosMT has been reported to produce rapid improvements in mental health (observed in some after 4 weeks of use) and there have been no reported complications or side effects. (Dobbin et al., 2009) Self-help tools such as PosMT may be particularly important in the context of stroke rehabilitation, since stroke survivors often have additional challenges to receiving psychological care such as the ability to attend services. With approximately 1.1 million stroke survivors living in the UK alone, (British Heart Foundation Health Promotion Research, 2012) training sufficient staff to manage the psychological needs of all stroke survivors would be cost-intensive. If effective, PosMT could be used as an additional self-help tool in rehabilitation for prevention or management of post-stroke psychological problems. (Koeser, Dobbin, Ross, & McCrone, 2013) It may also have a role for those with subthreshold or no symptoms to improve quality of life and aid coping with the stresses associated with rehabilitation. Half of carers for stroke survivors themselves experience mental health problems, (National Audit Office, 2005) and PosMT could also be offered to carers.

The aim of this qualitative study was to gain insight from stroke survivors and their carers regarding their experience of training in positivity using the audio-based

PosMT tool.

Methods

We captured experience of use and acceptability of the Positive Mental Training (PosMT) tool from stroke survivors and their carers through qualitative feedback and recording of adverse events.

Ethical approval was obtained from the London Bridge NHS Research Ethics Committee (REC:14/LO/0053) prior to commencement of the study.

Study Population

We drew interested members of the community - stroke survivors and their carers from existing support groups (Kings College London Stroke Research Patient and Family Group and the local Stroke Association Voluntary Support Group Peterborough, Bedford Stroke Association Support Group, and Different Strokes) to assist with the study. Volunteers were asked if they were willing to listen to the PosMT tool to provide feedback either on personal benefits or on whether they thought the tool would be useful for other stroke survivors.

Volunteers who had evidence of stroke and who were over 18 were invited to listen to the PosMT tool either online or on a CD. Those who lacked capacity to provide informed consent, had moderate to severe cognitive deficits or who were felt by their GP to be unsuitable on clinical grounds (including patients with significant receptive

aphasia) were not asked to participate. Those who did not speak any English were also excluded. Carers and caregivers of stroke survivors could listen to the audio alongside the stroke survivor if they chose to do so and participate in the interview. Stroke survivors and carers were screened to exclude severe depression and suicidality.

Questionnaires

Psychological scales completed at the point of consent were the Positive and Negative Affective Scale (PANAS),(Crawford & Henry, 2004) Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) or Depression Intensity Scales Circles (DISCs)(Turner-Stokes, Kalmus, Hirani, & Clegg, 2005) in case of dysphasia. Those who were severely depressed (HADS–D>15 or DISCs>4 or who respond ‘true’ to the BASDEC suicide question), were excluded and referred to their GP for further care for the sake of safety. The same measures were repeated at the time of interview.

Positive Mental Training (PosMT) intervention

A modified PosMT audio (with instructions re-recorded to ensure suitability for stroke survivors based on feedback by a stroke rehabilitation psychologist SR) was used. The modified tool consisted of 12 audio tracks each lasting 18 minutes, to be listened to everyday for a week with a different track each week. After obtaining written consent, stroke survivors were supplied with either a downloadable mp3 file or three CDs. Participants were informed that this programme was being assessed as a new intervention to help stroke recovery. They were asked to listen for the first four weeks (as effects may be seen in that time), but could carry on to listen to the whole

programme if desired. The first track focuses on physical relaxation, tensing and releasing muscles (Jacobsen Relaxation) and developing slow diaphragmatic breathing, the second track on a short cut to relaxation and a body scan;(Jacobsen, 1938) the third track visualises a state of calm ‘special place’ and the fourth track further develops mental visualisation of this calm state to help in carrying out goals. The remaining tracks address a variety of themes including self-confidence, problem-solving, creative thinking and visioning the future.

Participants received follow-up phone calls in the first 4 weeks to ensure that they were not experiencing any problems with listening to the audios. Qualitative semi-structured interviews were carried out by NM to capture stroke survivor and carer experience of use of the tool over the intervention period with regards to: likely benefits and harms of the modified PosMT tool to increase positivity and overcome post-stroke psychological distress; whether the tool is easy to use; if stroke survivors would adhere to it, how it might be adapted to best suit stroke survivors and whether it may be particularly useful in specific groups of survivors.

Interviews and Analysis

The interviews lasted on average between 30 to 45 minutes and were audio recorded and then transcribed verbatim by an approved external agency, checked for accuracy and entered into NVivo (version 10.0) software, which was used to allow for data management to organise transcripts and codes and for comparative analysis. Two members of the research team (NM and SR) carried out the analysis. Transcripts were read and reread by NM and SR and themes identified using a grounded theory

approach. Themes were identified until no further data could be described. A preliminary assessment of those most likely to benefit was made. All questionnaires were re-administered at the same time as the interview.

Findings

Four stroke survivors and one carer who volunteered could not be included in the study due to having severe depression or suicidality on the HADS and BASDEC questionnaires. The 10 stroke survivors admitted into the study represented a range of age, gender, physical disability level, time since stroke and level of aphasia, depression or anxiety (see table 1). Of the four carers who listened to the programme, two had borderline and two severe depression. Three reported severe anxiety on the HADS scale. The mean age of stroke survivors was 64.5 (SD13.1) and of carers 70.2 (SD6.6). Most participants chose to receive a CD rather than an mp3 file to listen to the PosMT tool.

Insert table here

Ten semi-structured interviews with stroke survivors were conducted, five of whom had carers present during interview, but only four who had volunteered to listen alongside the survivor. One stroke survivor did not wish to have any recording but agreed to have notes taken of the interview. Five of the interviews were held approximately one month after being given the PosMT. Five further interviews were conducted later when the participants had the opportunity to listen to more of the

recordings. In the following quotations I=interviewer, S=stroke survivor, C=carer.

Analysis of interviews demonstrated the following themes:

Willingness to listen

Stroke survivors who participated had all initially expressed a willingness to listen, although in some cases carers had initiated involvement. Most were keen to access and try a self-help and non-drug approach to psychological intervention:

S: I've always been pretty anti being labelled depressed or anything like that ... I've always been very very sceptical of medication I'm more for other approaches than for medication. (S1)

Although, participants originally agreed to listen to 4 weeks of the recordings, an elderly female stroke survivor with significant physical disability and aphasia and her carer said that they were too busy with family life to carry on and stopped listening after a week, although they were happy to participate in interview. Later at interview they reported that the audio had done '*nothing for us at all*', although they admitted that they felt they had not gone into it '*wholeheartedly enough*'. Later they suggested that they would have liked to have listened to more of the '*psychological bits*' of the audio and that timing was also a factor for them:

S: In six months time we might ring you up and say 'can we have it because we think now we might be able to appreciate it more' (C2)

Another female older stroke survivor with aphasia who was disabled requiring a wheelchair, listened to the recording as her husband played the CD, but said she preferred to be doing other activities rather than listen.

I: Why do you think she didn't listen to it? C: I don't know because she didn't like it S: No time ok, it's more fun at the Centre! (C3/S3)

The 8 remaining participants completed 4 weeks of listening and 5 of these carried on beyond four weeks.

Positive Benefits

(i) *Overall.* Seven of the ten stroke survivors reported positive benefits from listening, generally found the programme helpful and would recommend it to others. Comments included “*on the whole it was quite good ... I would recommend it to others*” (S4), “*very therapeutic*” (S5), “*I think it’s potentially a very useful tool*” (S6) “*very satisfying CD to listen to I do feel better in general, I think ‘oh, I do feel good’*” ... (S1)

(ii) *Relaxation, sleep, reduction of anxiety.* Relaxation, unwinding, and falling asleep were all major themes described by those who found benefit from the programme.

S: the majority of the time I must confess because I find it so relaxing I use it for that purpose when I need - I’ve gone over the top and I need to relax and unwind. I actually found your CD very therapeutic and relaxing I went to sleep that’s how relaxing it was for me.... (S5)

S: Yeah it does help with that because it’s I have a problem where I can’t slow down sometimes I’m just going like this the whole time and I’ve always got to be doing something and it’s like I find it quite difficult to just sit down. (S1)

Having the PosMT audio provided a mechanism to enable relaxation, through structuring relaxation time including some who preferred to listen at bedtime.

S: I mean if I hadn’t had the CD there I wouldn’t, I probably wouldn’t have taken a break. It’s like I know it’s there, I know I can have access to it and I’ve forced myself to listen to it and to spend half an hour or an hour just chilling (S1)

S: I listen to it at the same time every night before I go to bed so that helps me into a routine and I think towards the end of the week I tend to fall asleep before it’s finished because my body’s got used to that relaxation which is really good (S7)

One elderly stroke survivor living on her own, particularly found the PosMT comforting and relaxing, helping her feel less isolated.

S: The voice is comforting for me. Anything that gives a feeling of comfort is then that you're not alone in that respect. (S5)

Stroke survivors also reported benefits in handling stress and anxiety. One young 35 year old female stroke survivor suffered severe anxiety when alone as a result of her having had a stroke when she had been on her own during one of her husband's work trips. This survivor found listening to the PosMT helped her anxiety at being on her own while her husband was away:

S: It's really helpful for me because the post-stroke anxiety, I can listen to it whenever I need to which has been helpful the sleep deprivation is one thing that I've really suffered from. It's the anxiety of being in the house by myself. I know when I squeeze my hand and hold my breath (relaxation technique from CD) I can do that - bring in positive feelings - when I'm at work so if I'm a bit stressed... So the CD for me has been very helpful.... I had what I thought was another stroke and actually it was just a panic attack. I felt like I couldn't breathe, very restricted, so the CD for me has been very helpful. (S7)

(iii) *Confidence and coping.* Three stroke survivors described an increased sense of being able to cope with their daily life after listening to the PosMT. For example, the 35 year old female stroke survivor with post-stroke anxiety described how using the relaxation techniques from the audio gave her confidence and eased her anxiety regarding and ability to cope with return to work. Another stroke survivor felt on reflection that the PosMT may have helped her cope with traumatic events that had taken place during the period of listening:

S: Some people are quite cynical and don't believe in your subconscious but mine's very stubborn and very powerful and once you get through to it, it does make a big difference for me. It's (the stroke has) basically stripped away my self confidence and I'm slowly getting that back which is good." (S7)

S: Being able to listen to the CD on the train I worked out if I could ... listen to it twice on the train actually by the time I'd listened to it twice I'd already be at work so I could do it that way so actually I'd be relaxed. By the time I'd got to work I'd be so relaxed I didn't want to work. I'd be like 'really, this is a great place'! (S7)

S: Yes, well I've had three deaths in a week..... so in fact maybe it's helped me cope (S4)

(iv) *Mood, optimism, vitality, motivation and resilience.* A couple of stroke survivors reported an improvement in low levels of mood and lethargy and feeling energised and motivated from listening to the PosMT:

S: I was quite energised afterwards, I felt refreshed (S5)

S: Yes and also when you wake up you feel refreshed and quite motivated you want to do things It energises your feelings about things, not so much physical that comes later I think, but it energises your feelings (S8)

Letting go of worries allowed stroke survivors to be able to focus more positively and imagine a happier outcome with their rehabilitation and future in general. A couple of stroke survivors described how listening made them less fearful of having another stroke and how the PosMT made them feel more positive and optimistic with life. One stroke survivor described how going to her ‘special place’ where she was ‘positive’ and ‘strong’ helped her cope at times:

I: After you’d been listening did you feel a change in yourself? S: I think it did have a positive effect yes, I think I can say that I would say just a little more optimistic for the future. Maybe stopping thinking I could have another stroke at any minute, which I don’t do but those sort of thoughts are obviously there. Anybody who’s had a stroke has got to be slightly afraid of having another. I think a little bit more positively and I do still try and go to my ‘place’ to be calm and if I’ve got something coming up which is a bit challenging I’ll try and go to ‘my space’ and think of my board (image from CD) with ‘calm’, ‘positive’, ‘strong’ on it so it’s still there.(S6)

S: Yeah, so you see more on the positive side of things rather than the negatives, focusing on the negatives all the time which is easy to do really when you’ve had a stroke it’s easy to focus on negative, negative, negative everything’s negative.” (S8)

S: So the CD for me was able to put things into perspective and actually being able to take me to a place where I was happy in my past, and actually remind me that I can actually be that in my future again as well, so that’s where I am at the moment with the CD, so it’s being able to tie the two together. To go back to positive past experiences... and actually being able to link the two together and take that forward. So for me it’s quite an exciting place to be. (S7)

Positivity and motivation helped to enable one stroke survivor in particular to carry out a previously impossible task since the stroke. A wheelchair bound 65 year old

male stroke survivor who had lived with a stroke for the past 5 years and who had significantly physical disability and was suffering from borderline anxiety and depression described how listening to the PosMT audio had increased his motivation and resilience and ability to focus on activities, allowing him to regain the ability to perform a task he could no longer do since his stroke. This survivor also expressed how important it was to be able to do something for himself, no matter how small, and believed that the PosMT had encouraged him towards greater autonomy:

S: It helps you with your thinking...It's hard to explain really but it helps you to focus more on the positive side of...sometimes when my carer comes they put the cap on the toothpaste too tight, well before I would say 'well they've put the cap on too tight', then scream wolf and then get [carer] to come and take the cap off because I can't get it off. But now I will ... Try and try again. Try, try, try to get the cap off. It's only a simple thing to me, to you I: And can you?..... S: I can yeah, I can now ... I don't get so angry with it now I get more as though I'm more motivated and I think I'm gonna get the cap off, I'm gonna get the cap off. It's only a little thing that anybody else would do in a second but it takes me a while to do it, but I don't get frustrated about it now whereas before I would doit makes you somehow persevere more. It makes you, say grip a bit harder or turn a bit harder. It gives you that kind of... energy yeah, a bit more energy. (S8)

This stroke survivor also reported that listening to the PosMT audio had made him more adaptable and open minded to trying new things, and encouraged him to think further, more laterally and creatively of alternative options in the pursuit of achieving his goals:

S: Listening to the CDs..... it gives you more of a lateral way to go by saying try this, try this, try this, try this. It's like a pendulum, if you can't do something then try this, do a lateral movement and I think that all my life really has been set order, set order, set order but now I can look both ways. I can look on a pendulum laterally thinking and say 'well if that doesn't work what about going over here, what about going over here?' and so you might not reach a decision on anything so quickly but at least you'll get there in the end by going down the arrow. Go sideways and down. I: Right, so you see more options in your life in a sense? S: You have more balanced view of things instead of being all one sided about things. I think you agree with that [carer] won't you? C: Yeah it makes you more rounded doesn't it? In what you're thinking (S8/C8)

S: I think it's because it shows you that you can use what you have, what you've got left. You can use that to good effect without worrying because you do get a lot of

worry, a lot of stress and I think when you first have a stroke you go through a lot of mixed emotions as you no doubt know that you go through a lot of anger and why me, and all that sort of thing and you go through a lot of pity and stuff and other people do as well they pity you and all that kind of thing but somewhere along the line you've got to stop feeling sorry for yourself really but it's at that point, say after a couple of years or so, that you need a CD and somebody professional to guide you through that so that you can start again. It's all very well saying 'it's no good asking me to do that I can't do that' and you may be not able to do that but you can contribute maybe in other ways and I think listening to the CD they give you quite a clear direction on which way to go to be able to tap those resources. The resources of your brain are, well they're more... (S8)

This same stroke survivor also spoke of the PosMT helping him to focus on his remaining abilities since the stroke and to have greater acceptance of his present situation:

S: Yes and also when you wake up you feel refreshed and quite motivated you want to do things but that can be a bit frustrating because you want to do things and you can't do things and so you think well yes I could if, if, if. All the time it's if I was able to but you have to come to terms with things and I think the CD does help you come to terms with what you can do and what you can't do. It gives you a message, saying well it doesn't matter what you can do as long you can do this you'll be on the way to this..... You have to adaptI think the CD has helped me to adapt more to it (S8)

Barriers to listening, negative effects and suggestions to improve the tool

The biggest challenge to listening was not having time to fit the PosMT into busy lives, and not all volunteers were able to listen to the audio every day.

I: And what were the reasons that you didn't listen on those days?

S: I was just busy, really busy. I work and I do my garden so it's quite, I'm whizzing around all the time and if I'm not doing that I'm doing housework or So it's like, I'm full on a lot of the time (S1)

However, commitment to and giving the programme a chance was recognised as important since this would help reinforce the benefits. One stroke survivor, for example described how at the beginning she felt it was not for her but sticking with the tool found it more helpful. Practicalities such as one couple only having a CD player in their car or another who did not know how to work the CD player properly were barriers to listening. Conversely one couple and another stroke survivor who put

the programme on their ipod found this very helpful, making listening easy. Additionally making a routine was helpful.

S: I think most people would get into it if they just give it a chance but it's giving something a chance isn't it, to work? (S1)

Physical exhaustion as well as daily activities taking longer to complete following a stroke added to the burden of listening. One elderly stroke survivor explained how tiredness meant that she had to prioritise more essential activities. Another spoke of how much longer carrying out of activities took in the presence of a stroke, making the simple act of listening to a CD more difficult.

I: What were the reasons that you didn't listen on those days? S: I was just busy, really busy ... if you're paralysed like if your hand's paralysed or you're paralysed down one side you're going to have less time because everything's going to take three times as long to do (S1)

Mental concentration was also a problem for the three stroke survivors with the most disabling strokes who also had aphasia and became a barrier to listening and completing the programme.

*S: My brain doesn't cope with a lot these days does it?
I: Do you remember listening to it?
S: No, I did, I did listen, they said I weren't listening properly (S9)*

I: When you tried to put it on did she say turn it off? C: no, no she doesn't.... but she doesn't concentrate on it or you know (C3)

Negative effects of listening to the PosMT tool were minimal, although one carer reported that an older stroke survivor with aphasia was at times irritated when listening to the CD. No one however stopped listening specifically because it upset them. The interviewees generally expressed the view that there wasn't anything unsuitable in the content of the PosMT that would harm stroke survivors. One

survivor reflected that if someone didn't like the tool that it was easy to turn it off (which reflects the experience of those who disengaged).

S: Well people aren't that sensitive I don't think ..., they've got their handicaps and they know what they are. They're not going to burst into tears because of the tape I don't think there's anything offensive in the tape. (S1)

S: If it's too much they can just switch the damn thing off (S1)

Stroke survivors were specifically asked about aspects of the programme focussing on the visualisation of the future and of rehabilitation goals and whether it may upset them if they were later unable to carry out the task they had visualised. Concerns were not generally raised. However, one interviewee felt this may be a problem. The same survivor, however, also reported that the visualisation did make her feel peaceful, even though she was unable to physically carry out the task:

S: Just imagine yourself in this situation doing something that you don't do very easily And you know keep imagining it Fine my head might say I can get on a horse and go for a ride; my body's not going to let me do it. Not yet..... (S6)

S: Moments that you think I'm never going to forget this moment, when you're down if you can go to that place and relive it. When I think of myself galloping my horse up a hill in the Lake District and the view opening up..... one of those brilliant days, weather perfect on the top of a ridge. Not a soul in sight, right on top of the world and who'd want to be anywhere else – well I wouldn't [laughs] (S6)

She suggested that more specific instructions should be given to stroke survivors to carefully select rehabilitation tasks they feel they could improve on with greater confidence rather than to generally visualise a task they would like to carry out in the future:

S: Think if you say, if it was more... 'what do you find at the moment you lack confidence in doing' for example... Then find an area where I'm lacking in confidence? (S6)

Other feedback on how the PosMT could be modified for stroke survivors included comment regarding physical relaxation, with mixed views expressed as to how useful

Jacobsen physical relaxation would be to survivors and how much this should be included in the audio, although many did report benefit. A few felt that having an earlier taste of the positive psychology aspects of the audio and less physical relaxation would be more useful to stroke survivors. Comments were made about the voice by some and others did not find the music relaxing. Several stroke survivors commented that it may be difficult to have a programme that everyone likes, due to individual taste in voice, music and pitch and so choice would be helpful.

Who might benefit the most from the PosMT?

Stroke survivors and their carers offered suggestions as to which survivors they felt the tool may help the most. Although not everyone felt the PosMT was for them, all believed that the tool could be helpful to other survivors, with a couple suggesting that those with anxiety would be most likely to benefit.

S: Would recommend if someone has deep anxiety and worry as these (meditation/hypnosis) helped me with anxiety and worry (S10)

Review of stroke survivor interviews suggests that completing the PosMT resulted in the most positive feedback during interview and that commitment to the entire programme may be important for best outcomes. Time since stroke and degree of physical disability did not appear to be a barrier to reporting benefit. Those with depression or anxiety did appear to describe greater benefits. A survivor who found the programme the most useful had suffered a stroke 5 years previously and was wheel-chair bound. In general, older participants were less willing to listen to the tool. However, those who did reported positive feedback. The presence of significant aphasia, was however, a barrier to concentrating and listening and the three

participants with more significant aphasia did not continue to the end of the programme, mostly due to lack of interest in listening.

Feedback regarding use of the PosMT in carers

Both stroke survivors and their carers felt that addressing the mental health of carers was important and were keen to try any interventions that might help. Two carers who originally volunteered to listen to the PosMT and who were not depressed or anxious, however decided not to continue listening to the audio after a week. One carer, the husband of an older stroke survivor reported that the PosMT tool was not ‘for me’ and expressed how he “just didn’t relate to it”, although he was fully encouraging of his wife listening.

C: I think I had an open mind when I started it. I didn’t find it did anything to me at all.... It just didn’t click. I don’t react particularly to people telling me things [laughs]... But if it helps [wife] it helps, end of story as far as I’m concerned’ (C6)

The other two carers listened and found positive benefits. One carer described how she was now more patient and understanding with her husband and that the PosMT had helped her with negativity regarding her husband’s future with stroke. She also reported that the PosMT had helped them to get through a depressing winter.

C: I think I would say I’m more understanding of what [stroke survivor] has gone through and also, I am a patient person anyway, but I did used to get a little bit frustrated at times. You do because it’s out of your control sometimes when you can’t do something for somebody who’s had a stroke so I have felt more positive and it’s got us through this winter as well, much better, because in the winter you don’t tend to go out quite so much, do you, so that’s helped that way You can be very negative, and it can help you to get through that negative I think it just helps you just to relax and forget the rest of the world, forget your worries and concentrate on the future.” (C8)

In another situation where the stroke survivor said she was too busy to listen to the CD herself, she suggested that it would benefit her husband who was her carer. He

himself felt that the tool helped him to relax and to have more energy for his daily tasks including looking after his wife.

S: Yes, but he need it I: why do you say he needs it?

S: because he has time to listen to it You can go to bed you lie down there asleep with it..... relax him (S3)

C: Quite like it yeah I feel energetic yeah.... yeah it makes me fall asleep and then you know fall into a trance yeah.... good dreams... (C3)

Changes in psychological measures of stroke survivors

Four stroke survivors who participated moved up the positive scale of the PANAS and down the negative scale during the period of listening. One of these, a 35 year old female also moved from mild depression and moderate anxiety to no depression and mild anxiety on the HADS scale, while a 64 year old male survivor moved from mild anxiety and depression to no anxiety or depression. On the other hand, one elderly stroke survivor who had also listened to all 3 PosMT audios moved from borderline to severe anxiety and borderline depression. This participant had reported the PosMT to be helpful and relaxing, however, during the weeks of listening had several hospital admissions for atrial fibrillation, which she reported to have affected her psychological wellbeing.

Discussion

This exploratory qualitative assessment suggests that training in positivity for stroke survivors may be a potentially beneficial intervention to help with coping and the prevention or management of post-stroke psychological problems that interfere with rehabilitation. Specifically Positive Mental Training (PosMT) appears to be an

acceptable tool for use in stroke survivors and suitable for further trial. Our qualitative interviews with 10 stroke survivors and some with their carers suggests that while a few survivors did not find the PosMT tool to be suitable for them and did not engage with it sufficiently, a majority of survivors who listened (7 out of 10) reported positive physical and psychological benefits including improved relaxation, better sleep and reduced anxiety after 4 weeks of listening. Three stroke survivors who completed the full 12-week programme appeared to find the tool the most helpful and reported improved motivation, confidence and coping, and positive outlook with increased optimism with relation to the future and towards achieving rehabilitation goals. Interventions that focus on improving general wellbeing and reducing anxiety including cognitive behavioural therapy, relaxation and mindfulness meditation have shown benefit to stroke survivors. (Golding et al., 2015; Johansson et al., 2012; Lawrence et al., 2013) Training in positivity, however goes beyond addressing negative symptomatology and promoting relaxation and mindfulness, to help survivors to focus on positive outcomes by letting go of anxiety related to carrying out of tasks, and increasing motivation to attain goals. In particular, the PosMT has been developed based on sports psychology techniques where visualisation of future performance after positive emotional generation, a recognised technique for improving physical and mental outcomes has been employed. In our study we found that in two participants who suffered from post-stroke anxiety and depression, listening to the PosMT while visualising a future task aided with later successfully carrying out an activity of daily living in one participant, and in the other a more complex task of returning to work.

Based on reports from stroke survivors in our study, we found the negative effects of the PosMT to be minimal, although those with moderate aphasia found it difficult to concentrate and did not persist. When stroke survivors did not feel they received personal benefit, they nevertheless felt the tool could still be useful to others especially those with anxiety and difficulty coping with their stroke. Age, degree of physical disability or years since stroke did not appear to influence the kind of feedback received regarding the PosMT among our small group of stroke survivors, although those with anxiety or depression did appear to report greater benefits, while those with aphasia reported least benefits. Our findings, however, are limited by the fact that our sample was self-selected and this may have led to more positive reviews than a random sample of stroke survivors. On the other hand, since not all volunteers had clinical depression or anxiety and those with the most severe depression and anyone who was suicidal were excluded, reported benefits may have been minimised. Another short-coming was that stroke survivors were only asked to volunteer to listen for 4 weeks and only to continue if they wished and therefore not all went on to complete review of the full 12 week programme.

Our preliminary qualitative study nevertheless suggests that while the PosMT may not be suitable for all, it may be of benefit for those stroke survivors who are motivated to listen. Having a stroke presents a number of challenges to accessing and engaging with psychological services including problems with mobility limiting attendance at therapies, physical difficulties in engaging with computer-based programs and often difficulties in verbal communication. Our study suggests that since the PosMT requires only daily listening by the survivor at home for less than 20 minutes a day, that it is nevertheless an acceptable and easily accessible tool for many stroke

survivors. After a few hours of initial training, the PosMT also requires no other expertise to deliver and could be offered to stroke survivors by any health professional including primary care staff. It is also a very low cost intervention at around £38 (\$57) for the full audio programme. (Koeser et al., 2013) Further it can be used alongside antidepressant medication and other psychological therapies. For carers, listening with survivors may provide additional benefits. Development of the PosMT to benefit also those with more significant aphasia is a further important step in development of the tool before trial.

In short, we believe trials of this and other tools that promote positivity, resilience and coping in stroke survivors and counter psychological problems including anxiety and depression are warranted. Some argue that health services should minimise over-optimism and engage with stroke survivors regarding possible disappointment with progress in rehabilitation. (Wiles, Ashburn, Payne, & Murphy, 2004) Positivity training, however, we believe should aim to develop a ‘realistic optimism’ in survivors. (Schneider, 2001) Adapting training in positivity to the specific needs of stroke survivors is crucial.

Declaration of Interests

This work was supported through the Royal College of General Practitioners (RCGP), UK Scientific Foundation Board, United Kingdom. Positive Mental Training has been developed and produced by AD & SR, and the copyright is held by Positive Rewards Ltd (SR is shareholder). AD and SR were not involved in data collection.

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Table 1: Demographic and other characteristics of study participants

Study ID	Age	Gender	Years since stroke	Physical Disability (Clinical)	Aphasia (Clinical)	Anxiety (Hads-A)*	Depression (Hads-D)†	PANAS Positive ‡ (percentile)	PANAS Negative § (percentile)
<i>Survivors</i>									
S1	54	M	1	None	None	None	None	21	28
S2	74	F	1.5	Severe	Moderate	Mild	Mild	98	81
S3	81	F	6	Severe	Moderate	None	None	41	18
S4	64	F	1	Mild	None	Mild	Mild	41	94
S5	75	F	3	Mild	Mild	Mild	None	62	63
S6	65	F	1.5	Mild	None	None	None	36	28
S7	35	F	1.5	Mild	Mild	Moderate	Mild	28	91
S8	64	M	5	Severe	Mild	Mild	Mild	13	18
S9	73	F	10	Severe	Moderate	None	Severe	8	47
S10	60	F	7	None	None	xx	xx	xx	xx
<i>Carers</i>									
C2	74	M	N/A	N/A	N/A	Mild	Mild	98	81
C3	77	M	N/A	N/A	N/A	Mild	Mild	13	94
C6	68	M	N/A	N/A	N/A	None	Mild	88	74
C8	62	F	N/A	N/A	N/A	Mild	None	81	90

* HADS-D Hospital and Anxiety Depression Scale - Depression
† HADS-A Hospital and Anxiety Depression Scale - Anxiety
‡ Positive and Negative Affective Scale (PANAS) - Positive Score
§ Positive and Negative Affective Scale (PANAS) – Negative Score